





Sudden Infant Death Syndrome

Acknowledgements

Project Coordinators

- Marcia Noonan, R.N., P.H.N.
- Elsa Weber, M.S., CHES

Editor

 Gwen Edelstein, R.N., P.N.P., M.P.A. Program Director California SIDS Program

Contributing Authors

- Gwen Edelstein, R.N., P.N.P., M.P.A.
- Deborah R. Gemmill
- Thomas G. Keens, M.D.
- Marcia Noonan, R.N., P.H.N.
- Penny Stastny, R.N., P.H.N.
- Elsa Weber, M.S., CHES

Special Thanks to the following SIDS County Coordinators

- Betty Cofield, P.H.N., M.P.H.
 Los Angeles County Health Department (retired)
- Dawn Dailey, P.H.N., M.S.N.
 Contra Costa County Public Health Department
- Patti Harmon, R.N., P.H.N.
 El Dorado County Health Department (retired)
- Judy Keswick, P.H.N., M.S.N. Butte County Health Department
- Penny Stastny R.N., P.H.N.
 Orange County Health Care Agency (retired)

Graphic Design

• Newsletters, Etc.



This is copyrighted, but may be reproduced without permission.

We request that proper credit be given to:

California Department of Health Services/California SIDS Program

Produced by the California SIDS Program under funding by the California Department of Health Services, Maternal, Child and Adolescent Health Branch © 2005

DEATH SYNDRONE
CALIFORNIA BERMANKET
BOO-369-SIDS (7437) • www.californiasids.com

Forward

This poem, "Could You Please Just Listen?" was written by a SIDS parent, Deborah R. Gemmill in response to the question so many well meaning people asked after her son Tyler died from SIDS. They asked, "How can I help?" Deborah's response was simply, "Could you please just listen?"

My baby has died. Please don't tell me you know how I feel. You don't. You can't. I hope you never do. Don't tell me that he's with God and I should be happy. How can I be happy when every time I go into his nursery all I see is an empty crib and toys that will never be played with? How can I be happy when my arms ache to hold him?

Please don't tell me God needed another angel. It's hard for me to understand God would take away this little one who was so loved. Maybe I'll understand later. But for right now...let God find another angel. Please, please, please don't tell me I'll have other children. Maybe I will...but my son was not a puppy that ran away...he cannot be replaced.

Maybe you could just listen when I remember out loud all the things we did together...the walk, the early morning feedings, the first time he rolled over. Maybe you could just sit with me while I cry over all the things we'll never do together.

Please don't tell me it could be worse. How?

I really don't want to hear about your grandfather's death. It's not the same. Don't think my pain will be eased by comparison. Of course I'm glad that he didn't suffer, but I'd be a lot happier if he hadn't died at all.

I know it must be hard for you, but would you mind looking at his picture just one more time, we don't have many of him and I'm just a little bit afraid that I may forget what he looked like. He wasn't here that long you know.

Could you please just listen?

Don't tell me I'll get over it. There is no "over it," only through it. Please don't tell me I should be glad he was just a baby, or that at least I didn't get to know him. I knew him before I ever saw him. He is a part of me. And now he is gone. I haven't just lost a seven-month old baby. I have lost a part of myself.

I know you mean well, but please don't expect me to tell you how to help me. I'd tell you if I knew, but right now I can hardly put one foot in front of the other. Maybe if you looked around, you could find some things to do, like taking my daughter for a walk, or doing the dishes, or making some coffee. Please don't try to remove my pain or distract me from it. I have to feel this way now.

Maybe you could just listen.



© Getting Through Grief: From a Parent's Point of View

Introduction

Sudden Infant Death Syndrome (SIDS) is a medical and psychological crisis. The sudden and unexpected nature of SIDS is a crisis for which no one can truly prepare. It is an event that will never be forgotten, which brings great sorrow, and that will change the parents' lives forever. The public health nurses and/or health professionals who provide the early intervention, support, counseling and comfort to the family after the baby's death play a vital role in assisting them through the SIDS experience.

The SIDS community has long recognized the importance of providing early and continuous support and comfort for newly bereaved parents. Those who have experienced a SIDS death know all too well that once first responders have provided their professional services they quickly disperse, often leaving families without the support they require to survive. Because of that, members of the SIDS community have worked long and hard for legislation that requires and funds the SIDS home visit. For many families the home visit is the cornerstone of their support.

The public health professionals* making the home visit are in a unique position to address the family's needs. The health professional can help alleviate guilt, pain and suffering by providing information in a sensitive manner, explaining autopsy results, providing community resources, and offering guidance for surviving children. Parents consistently report on the benefits associated with the SIDS home visit.

However, SIDS leaves an emotional impact on everyone touched by it, including the health professionals that provide care and support for the family. The purpose of this guide is to assist public health professionals in preparation for their role in the SIDS home visit. It will provide information about the essential skills that are required for the effective support to families, identify ways the professional may be personally affected, and provide suggestions on how to personally cope with the emotional impact of SIDS.

* Section 462 of the Health and Safety Code defines the designated agent of the local health officer as a trained public health professional who is a public health nurse or a social worker. For the purposes of this training manual, the term public health nurse is synonymous with "trained public health professional."

Table of Contents

The History of CIDS I existerion	1
The History of SIDS Legislation	
Sudden Infant Death Syndrome	
Notes	
Notes	30
Tables	
California and U.S. SIDS Rates 1980-98	4
• Sleeping Position of SIDS Victims and Controls	24
• Infant Sleeping Position and SIDS in the USA	
Relative SIDS Risk of Prone and Side Sleeping	
Predictors of Prone Sleeping in Infants	28
Cigarette Smoking and SIDS	30
Factors in Sleeping Environment and SIDS Risk	32
• Risk of SIDS in Subsequent Siblings of SIDS Victims	35
Section Two—Preparation for the Home Visit	
Before the Home Visit	2
Assessment Checklist	
Preparing for a SIDS Home Visit	
Sample Letter For Family	
Public Health Nurse and Coroner Teaming	
Grieving Parents: How Can You Help?	15
Talking to Children About Death	
Questions the Nurse May Ask	
Infant Sleep Positioning and SIDS: Counseling Implications	
Distributing Educational Materials: What Works?	27
Sudden Infant Death Syndrome Informational Portfolios	29
Modifying the SIDS Informational Portfolios	
Reporting Public Health Nursing Services	35
Public Health Services Report Worksheet	
Report of Contact Worksheet	43
Instructions	
Definitions	
Sample of Contact Not Established	
Sample of Service Refused	
Sample of Contact—Infant's Primary Care Provider	
Notes	54
Tables	
Assessment Checklist	3
• Issues, Concerns, and Practical Solutions	
How Children React to Death	
The contract of Death contract of Death contract of the contra	20

▶ Section Th	ree—The Home Visit	
Interviewing	The Family	
	Grieving	
	nd Cultural Sensitivity	
	SIDS Families	
	ing With Interpreters	
Debriefing, 7	ur—After the Home Visit Taking Care of Yourself	
	nal Impact of a SIDS Incident	
	Stress	
It's The Little	e Things That Will Get You Every Time!	7
	-	

NOTES



This is copyrighted, but may be reproduced without permission. We request that proper credit be given to:
California Department of Health Services/California SIDS Program

Produced by the California SIDS Program under funding by the California Department of Health Services, Maternal, Child and Adolescent Health Branch © 2005

California Sudden Infant Death Syndrome Program 800-369-SIDS (7437) • www.californiasids.com